

Supplementary file 3 – Summary of analysis of Phase 1 and 2 interviews to develop refined messages

Messages (Phase 1 rating in top 5)	Phase 1 - prioritising Summary Patients' comments N = 30	Phase 2 - rephrasing Summary Patients' comments N=29	Phase 2 Rephrasing suggested by patients	Research team conclusions and refined message
<p>1. HPV is a very common virus that most sexually active people will be exposed to at some point in their life.</p> <p>Phase 1 rating: 17/30 participants included this message in their top 5</p>	<p>Many patients agreed that this was a reassuring statement and that they were not to blame: <i>"It's just unfortunate, like all illnesses."</i> However, they felt that people should be more aware, and one patient found it alarming to read. Another suggested merging it with message 6.</p> <p><i>"Quite reassuring... you're not like a leper or something... you don't want to think it was your fault"</i></p> <p><i>"Most, that could be everybody.... it's important because I thought, Jesus, everyone has got it then, probably and when I first saw this I thought: what have I done?"</i></p> <p><i>"If you lead a normal life you have a high chance of HPV"</i></p> <p><i>"This puts it into perspective, it is common, it doesn't always end up causing cancer."</i></p> <p><i>"I didn't realise that most people carry the virus. It is important to tell my children and my friends about this; everyone should know this – it makes you more aware."</i></p>	<p>Most patients commented that this is a very useful statement but not many offered suggestions for rewording. One patient commented that it gives the impression that it only concerns people who are sexually active <i>now</i>; it doesn't indicate that it is relevant to people who were sexually active in the past. One questioned the wording "exposed to" and whether it meant you had been at risk of catching it and you didn't, or that you did. One wondered if something like a mind map would be useful, where the key point was central and other points in boxes leading off (a bit like our 'extra layers' of information)? One suggested combining messages 1 and 6.</p> <p>Patients commented that the messages in this group (messages 1, 3, 10) are clear with no particular overlap and are usual to the public.</p>	<p>HPV should be written out, otherwise easy to confuse with HIV: <i>Human Papillomavirus (HPV)</i> is a very common virus...</p> <p>HPV is a very common virus that most sexually active people will be <i>exposed to and acquire</i> at some point in their life.</p> <p>... that most people who are or have been sexually active will have been exposed to...</p> <p>HPV is a very common virus that most (how many? - add percentages) sexually active people will be exposed to at some point in their life, no matter what your age. You don't know how long in the future it will be before it shows, if at all.</p>	<p>HPV is a virus that is passed during sex or intimate contact. It affects both men and women, and it is so common that most of us get it at some point in our lives.</p> <p><i>Combining messages 1, 2 and 6 to simplify and address comments about repetition. NB heading of the script will have human papillomavirus written in full to address comment about confusion with HIV.</i></p>
<p>2. HPV infection is common in both men and women and is often shared between partners.</p> <p>Phase 1 rating: 6/30 participants included this message in their top 5</p>	<p>Patients thought this was useful information which could be used to break someone in gently, although patients with no partner did not find it relevant. Others felt it repeats information provided in other cards. Patients worried about their partners, and also thought that it is important to balance this out between men and women.</p> <p><i>"You worry about your partner and what could happen to them... Could he get something, should he be tested, should he go and see the doctor?"</i></p> <p><i>"You should be able to talk to your partner about this, to know that both of you can have this, and that it often gets passed on."</i></p> <p><i>"...men's old fashioned attitude, it would have been given to them by the wife, not vice versa."</i></p> <p><i>"lots of people don't think that men can get the HPV virus; young men and boys in schools should be told about this."</i></p>	<p>Patients were happy with this statement and its wording, although one commented that people might worry whether they should know they might have HPV (citing cases where people with HIV have been prosecuted for deliberately infecting others). It was suggested that this message should be merged with message 1.</p> <p><i>"Very plain and very common. Most people would understand that."</i></p> <p>Another felt it would be better to present facts and figures where possible:</p> <p><i>"HPV infection is common in both men and women' raises the question what does that mean, 20%, 5%, 30%?"</i></p>	<p>HPV infection is common in both men and women and is often shared between partners <i>although people would not commonly be aware of their HPV status as testing for HPV is not possible</i> (or feasible as so many people potentially carry the virus).</p> <p>Most men and women will have an HPV infection at some stage and this is often shared between partners. Or: HPV infection will affect most men and women at some stage (and possibly add figures to quantify 'most')</p>	<p><i>This message was split: a) to combine with message 1 above to simplify and include men and women in that message. b) to create a new message about sharing infection between partners, see message 25.</i></p>

<p>3.</p> <p>Infection with certain HPV types causes all cervical cancer, almost all anal cancer and can also cause some other cancers such as penile, vulvar, vaginal, and head and neck.</p> <p>Phase 1 rating: 16/30 participants included this message in their top 5</p>	<p>Most patients were not aware of this and some patients felt this was a lot (possibly too much) to take in, when you are preoccupied with your own cancer. However, that it was important to know, if scary. An awareness of what HPV can do may make people look a little bit more for symptoms. Several felt it should be talked about in schools. Also it was hard to absorb the fact that cancer can be caused by an infection. One patient thought this message was included in message 20, and another said that this message with 4 and 5 plus 23 answered all her questions.</p> <p><i>"I would not particularly <u>want</u> to know that at that stage (i.e. diagnosis). I'd think oh God, have I got another four cancers to go" (but she laughs at that)</i></p> <p><i>"People need to be aware that HPV causes these cancers, but not in a way that frightens them."</i></p> <p><i>"Although I was focussing on what I had, I think it's important to know about these other areas."</i></p>	<p>There was mixed reaction to this statement. Some felt it was factual and they understood it. Others wondered if this message might make people worry they will get these other cancers as well. One patient felt that the single cancer message was more helpful, although two others thought the single cancer message could be scrapped. Another did not fully understand and thought there must be different types of HPV and we should be more precise. One patient did not understand the word 'penile' but said she would have understood 'cancer of the penis'.</p> <p><i>....."I didn't know this; as it lists all the places where you can get it, it makes people worry they'll get these other cancers as well; it doesn't outright imply it but it hints at that, it puts in your mind that thought."</i></p> <p>One patient wondered about testing for HPV:</p> <p><i>...."Even with all this, is there no way for testing for it?"</i></p>	<p>ADD</p> <p>There is no proof to suggest that having any of these cancers makes you more susceptible to the others.</p> <p>Infection with certain HPV types causes all cervical cancer, almost all anal cancer and can also cause some other cancers such as penile, vulvar, vaginal, and head and neck. (go into detail here, eg HPV type X causes A, HPV type Y causes B).</p> <p>ADD. This does not mean having cancer in one area of your body will lead to it occurring somewhere else as well.</p> <p>... causes all cervical cancer, almost all anal cancer and can also cause some other cancers such as head and neck, penile, vulvar and vaginal.</p> <p>Simplify: The majority of the following cancers are caused by HPV ...</p>	<p><i>'Certain HPV types' replaced with 'HPV' to avoid the misunderstanding that different types cause different cancers.</i></p> <p><i>Message adapted to each cancer-specific script by putting the relevant cancer(s) first and quantifying it, and thereby remove the need for the single-site messages:</i></p> <p>HPV causes all cervical cancer, nearly half of vulvar and two thirds of vaginal cancers. It can also cause some cancers of the anus, penis, and head and neck.</p> <p>HPV causes nearly all anal cancers. It also causes cervical cancer and some cancers of the vulva, vagina, penis and head and neck.</p> <p>HPV causes about half of head and neck cancers (which can involve the tonsils, tongue base and soft palate). It also causes cervical cancer and some cancers of the vulva, vagina, penis and anus.</p>
<p>4.</p> <p>HPV can usually be cleared by the immune system but occasionally, it stays in the cells of the affected area for several years. This persistent infection causes changes in the cells that may lead to cancer.</p>	<p>Some patients thought this was important but were not very clear why. Others related their cancer to the fact that they had problems with their immune system in the past. Some did not find it useful information. Another thought it similar to message 5.</p> <p><i>"Helped me to make sense (of why I got this cancer) because my immune system is poor."</i></p>	<p>Some patients thought this could be linked with Message 5. One wondered about the description of HPV as a virus in message 1 and an infection here. Another thought the words 'persistent infection' implied something can be done about it. Another agreed that the general perception being that you go to the doctor and get antibiotics for an infection. These things could be quite different to a lay person. One patient thought his HPV infection took place in his 80s and had thought that the failure or suppression of his immune system is something that happened in the last few years rather than</p>	<p>HPV can usually be cleared by the immune system but occasionally, it stays in the cells of the affected area for several years. This persistent infection causes changes in the cells that may lead to cancer.</p>	<p><i>In H&N message, 'two-thirds' is changed to 'half' to reflect a more recent UK study.</i></p> <p><i>A further message was created to address the questions of risk of another cancer at a different site or in a partner, see message 26</i></p> <p>HPV is usually cleared by the body's own defences but, in a few people, it stays in the cells of the affected area for several years. Then it sometimes causes the cells to change, and that may lead to cancer.</p>

<p>Phase 1 rating: 15/30 participants included this message in their top 5</p>	<p><i>"I thought it might have been a time when I lost my job and was depressed and anaemic, very low. That might have been the time."</i></p>	<p>something that happened decades ago. So the card contradicts his understanding that the HPV virus can be in the body for 10-20 years and then some suppression of the immune system could cause the process that leads to cancer.. Another patient thought the word 'occasionally' was confusing. Did it mean today, tomorrow? One thought it will be a bit of a shock to people to realise that a person can carry a virus for very many years before it harms them. One patient worried that they could get another cancer in another part of his body. The idea of infection persisting seemed to indicate to him that it could still be there. A cervical cancer patient said that the doctor had told her that the type of cancer she had must have come from HPV, and therefore she must have been infected with it at some points – which she found confusing and also wondered whether her husband could still have the virus and re-infect her?</p>	<p>This persistent <i>virus/viral</i> infection causes changes in the cells that may lead to cancer.</p>	<p><i>'Immune system' and changed to 'body's own defences' and 'persistent infection' removed because these terms were poorly understood.</i></p>
	<p><i>"It's almost like saying, 'well, you're one of the unlucky ones'. It doesn't help knowing this afterwards."</i></p>	<p><i>"There is nothing you can do about it so what's the point in worrying about it."</i></p>	<p>..it stays in the cells of the affected ...for several years ..(perhaps make clearer it could be a very long process)</p>	<p><i>'Occasionally' changed to 'in a few people' for clarity.</i></p>
	<p><i>"....that's a good one, that's positive- that it can be cleared but if you are the carrier that would not make any difference at all."</i></p>		<p>Quantify and clarify 'several years'...it could be a lifetime?</p> <p>HPV can usually be cleared by the immune system but occasionally in a few people, it stays in the cells of the affected area for several years. This persistent infection causes changes in the cells that may lead to cancer.</p>	
			<p>HPV can usually be cleared by the immune system, <u>and more often than not does no harm whatsoever</u>, but occasionally it stays in the cells ...</p>	
			<p>HPV can usually be cleared by the immune system but it <u>may lie dormant</u> for several years and in some cases may lead to cancer.</p>	
<p>5. Even if HPV causes cells to change, it can take 10 to 15 years or more for cancer to develop.</p>	<p>Some patients thought the time lapse was interesting and useful to know about and helped them feel less guilty; others thought it irrelevant, and one found it baffling. Another felt it was reassuring because she could blame it on her ex-husband, having been her current husband's only partner. Another thought it was almost the same as message 8.</p>	<p>Several patients thought it a good and clear factual statement which is useful to know, but had not realised it can take so long to develop.</p>	<p>..it can take 10 to 15 years or more (<i>emphasise the 'or more' better</i>)</p>	<p>Even if HPV causes cells to change, it can take another 10 years or more for cancer to develop.</p>
<p>Phase 1 rating: 13/30 participants included this message in their top 5</p>	<p><i>"Cervical cancer makes you feel guilty. This tells you it wasn't your fault. If you're going to get it, you're going to get it".</i></p>	<p><i>"this implies you couldn't have done anything, it sort of reassures you a little bit."</i></p>	<p>Even if HPV causes cells to change it <u>could</u> take an average of 10-15 years for cancer to develop.</p>	<p><i>'10 to 15 years or more' changed to '10 years or more' so that people don't relate back to partners of 10-15 years ago.</i></p>
	<p><i>"Important because of my personal situation having been together with my current husband for 40 years."</i></p>	<p>However another found it surprising there is nothing to warn you that there's something wrong. One patient felt it should be made clearer that it could be longer than 15 years so people stop worrying (her husband had been dead 15 years) and another because she and her husband have been in a very long and faithful relationship. One misunderstood and, as she had had gastro-oesophageal cancer 15 years before, it had been lying dormant and explained her current cancer.</p>		
	<p><i>"This is just about the time it took, nothing you can do now..."</i></p>			

<p>6. You get HPV from having sex or intimate contact with another person.</p> <p>Phase 1 rating: 5/30 participants included this message in their top 5</p>	<p>Some thought that this message, although important, was obvious and was included or implied in other messages and could be combined with other messages (1, 12, 14, 15). Several felt it is important information for younger people as they change partners more frequently.</p> <p><i>"I'm not worried about this as I've been with the same partner for 9 years; this is more relevant is you have different sexual partners; for younger people this is a bit of a worry as they change partners more frequently; this is an important message to be passing on to my children."</i></p> <p>Although patients did not rate this message in the top 5, they identified it as an important message and as useful general information for the public but not totally relevant; however, on first reading, one patient had the immediate reaction <i>"could I have prevented it?"</i>, then later decided it was really irrelevant because you can get it either way. Another felt that by saying condoms don't help, <i>"that it is almost saying like it's not your fault"</i>.</p> <p><i>"There's nothing you can do now to alter things."</i></p> <p><i>"it's almost like closing the gate after the horse has gone; what's the point"</i></p> <p><i>"Relevant to prevention but not after diagnosis"</i></p>	<p>Patients thought this statement useful, but two thought it was superfluous and messages 1 and 6 could be combined. One patient that, although informative, it might make people go into panic mode. He thought the other messages in this group helped explain this, but that people would need more reassurance overall. Another thought this overlaps with message 14. Another agreed there is some overlap in this group. Another felt there was too much about sex generally. <i>"It's all about intimacy, isn't it. It's too much."</i></p> <p>Several patients commented on this message. Two thought it was a good idea, another did not see its relevance. One found it rather disconcerting and disappointing, and the question that came to mind was 'why?'</p> <p><i>"...this statement seems to provoke the question, well, how can I protect myself, and others, then; it raises a question rather than provides an answer."</i></p> <p>Another thought it important but needed more explanation, but could not think of a way to reword it.</p>	<p>Combine with 1 to soften this statement: <i>...will be exposed to at some point in their lives. You get HPV from having sex or intimate contact with another person who already carries/has the virus</i> HPV is a very common virus that most sexually active people will be exposed to and acquire at some point in their life through sex or intimate contact. Practising safe sex gives no guarantee that you won't be susceptible to HPV.</p> <p>Add info here: <i>And unprotected oral sex can also entail a risk.</i></p> <p>Although it is a good idea to use condoms to protect your sexual health, they do not provide complete protection against HPV <i>because there are other ways to pass it around.</i></p> <p>Condoms <u>do not provide complete protection against HPV</u> Change 'had' to 'have'</p> <p>Most people never know they had HPV because there aren't any symptoms <u>from an HPV infection</u> so there is no way of knowing when you got HPV or who you got it from.</p> <p>ADD percentages if known about how common it is: eg 80-90% of the population have an HPV infection at some point....</p>	<p><i>This message combined with messages 1 and 2 to avoid repetition.</i></p> <p>Condoms would not have given you complete protection against HPV.</p> <p><i>Taken out 'Although it is a good idea to use condoms' and tense changed to leave a message that addresses the question 'could I have done anything to prevent this?'</i></p> <p><i>'provide' changed to 'given you' to simplify and make more personal</i></p> <p>Most people never know they had HPV because there aren't any symptoms. It is hard to know when you got HPV or who you got it from.</p> <p><i>Split into 2 shorter sentences to improve readability.</i></p> <p><i>'There is no way of knowing' changed to 'It is hard to know' for accuracy and simplicity.</i></p>
<p>7. Although it is a good idea to use condoms to protect your sexual health, they do not provide complete protection against HPV.</p> <p>Phase 1 rating: 2/30 participants included this message in their top 5</p>	<p>Patients found this an important message although not relevant to know if you have had more than one sexual partner, but also because your immediate thought is "how did I get this?". Some felt that if there are no symptoms then there is no way of knowing who you got it from, which means there is no one to blame. For others there was a guilt that they should have spotted it earlier. Others wondered whether it was useful to know, as there is nothing you can do. Some patients confused cancer symptoms with symptoms of HPV. Another suggested combining message 8 with 23 to soften the effect.</p> <p><i>".... would you be racking your brain thinking was it Tom, Dick, or Harry or whatever?"</i></p> <p><i>"...so this is not giving you anything (i.e. there's no point in knowing this)."</i></p>	<p>4 patients thought this was a useful message and shows that there is nothing you could have done to make things any better.</p> <p><i>"So I could have got this at any time..."</i></p> <p><i>"That's true, people don't know anyway because it doesn't affect them; it's a lucky dip whether you get it or you don't, and it's not a very good prize."</i></p> <p>However one patient commented that this message needs clarification as there are symptoms of cancer</p> <p>A further two queried the use of the term 'had' which would indicate that any infection has gone, whereas other statements indicate there is a good chance you could have it in your system. Another worried about the idea that people would think their partners had been unfaithful.</p>	<p>Most people never know they had HPV because there aren't any symptoms <u>from an HPV infection</u> so there is no way of knowing when you got HPV or who you got it from.</p>	
<p>8. Most people never know they had HPV because there aren't any symptoms so there is no way of knowing when you got HPV or who you got it from.</p> <p>Phase 1 rating: 16/30 participants included this message in their top 5</p>				

<p>9.</p> <p>Having a diagnosis of HPV-related cancer doesn't mean you or your partner have had sex with someone else.</p> <p>Phase 1 rating: 8/30 participants included this message in their top 5</p>	<p>Patients found this a reassuring and important message to help people avoid feeling guilt or shame about what has gone on in the past, and to avoid blaming their partner. However, they did not see the relevance if they were not currently in a relationship.</p> <p><i>"People go into a relationship trusting each other – this is reassuring."</i></p> <p><i>"important because you could sit there feeling so guilty and bad about yourself; it's important to me and to other people because you've got an illness to deal with, you don't need to feel any shame or guilt because of what has gone on in the past."</i></p> <p><i>"If it's sexually-transmitted, one of you must have had sex with somebody else – maybe should say "you or your <u>current</u> partner."</i></p> <p><i>"Initially that was the first thing I thought."</i> (ex-husband's infidelity)</p>	<p>13 patients commented on this message, 6 patients thought this was an important message. Another was surprised and wondered how did they get it then if it passed from one person to another; the message should go on to say that they have got have had a former relationship.</p> <p><i>"...But it must start with someone, you must have got it from somewhere, so make it clearer it could have been a previous relationship. On first reading this statement it triggered the question whether HPV was an STD in the traditional sense."</i></p> <p>Others were concerned about this aspect too. The wife of a patient commented that this is a strange message as it means that one of them would have had to have had sex with someone else, and that would be incorrect for them. Another had the same thought:</p> <p><i>"..If you've only had one partner, and you've got it, then where did you get it from? So you will assume that either it was inherited in your blood, or that it was the partner..."</i></p> <p>One patient asked whether she might have passed HPV to her husband, and whether he was at risk.</p>	<p>ADD: Infection may have taken place decades previously.</p> <p>... doesn't mean you or your partner have had sex with someone else (add that this could have been in a previous relationship)</p> <p>change to: ...have had sex with someone outside the current relationship</p> <p>Having a diagnosis of HPV-related cancer doesn't mean you or your partner have had sex with someone outside the relationship.</p> <p>add wording which makes it clearer that it doesn't have to be within your current relationship but at some point you must have had sex or intimate contact with someone else for HPV to have been passed on.</p> <p>It needs to be made clearer that this refers to a situation where a partner would be suspected of having sex with someone outside the relationship (but no suggested rewording)</p> <p><i>Pre-grouping</i> HPV targets tissue known as mucous membrane (<i>which is</i>) found in the mouth, the anus and the vagina.</p> <p>HPV is transmitted via the moist red or pink tissue known as mucous membrane, such as can be found in the mouth and throat, e.g., tonsils and tongue, and also the genitalia.</p> <p>add where this tissue can be found in the body, be more specific: 'which is in your mouth' etc</p> <p>HPV targets the moist red or pink tissue known as mucous</p>	<p>Having HPV-related cancer doesn't mean you or your current partner have had sex with someone else.</p> <p><i>'a diagnosis of' removed to shorten the message for readability, and 'current' added to clarify that there might have been other partners in the past.</i></p>
<p>10.</p> <p>HPV targets the moist red or pink tissue known as mucous membrane.</p> <p>Phase 1 rating: 4/30 participants included this message in their top 5</p>	<p>Only 4 patients chose this message in the top 5, but many made comments. Most people found difficulty understanding the terminology or its relevance. Some gave suggested rewording. Others found the meaning clear. One patient thought this would be best presented in the context of French kissing. (<i>This partly occasioned by interviewer explanation that transmission is from mucous membrane to mucous membrane which she stressed to alleviate his concern that he might be able to pass HPV on to his children.</i>)</p> <p><i>I didn't really understand what this meant, or what its significance was, 'moist red or pink tissue', what's that?"</i></p> <p><i>"The words 'mucous membrane' might confuse some people. It could be simplified maybe, it's a clinical word."</i></p> <p><i>"Does this mean the places that the air can't get to?"</i></p>	<p>Similarly to phase 1, many patients made comments. There was confusion about where or what the moist tissue (mucous membrane) is. One suggested presenting it with message 3.</p> <p><i>"Am not clear what mucous membrane is – have heard of it but not sure where it was."</i></p> <p><i>"Anything with the word 'moist' has a problem – I think noses as well, and eyes."</i></p> <p><i>"Add more to this statement....about the areas of mucous membranes...because before this we never thought about the mouth as a sexually transmitted area."</i></p> <p>One patient found this message very confusing, and viewed it as a preventative message. He thought the point of the message mentioned colouring, was that to check whether the tissue was discoloured. Another patient did not think this message was necessary; <i>"you don't really need to know the biology of it"</i>.</p>	<p>HPV targets tissue known as mucous membrane (<i>which is</i>) found in the mouth, the anus and the vagina.</p> <p>HPV is transmitted via the moist red or pink tissue known as mucous membrane, such as can be found in the mouth and throat, e.g., tonsils and tongue, and also the genitalia.</p> <p>add where this tissue can be found in the body, be more specific: 'which is in your mouth' etc</p> <p>HPV targets the moist red or pink tissue known as mucous</p>	<p>HPV targets a type of cell found in the lining of parts of the body that only come into contact during sexual intimacy.</p> <p><i>Simplified for readability and the words 'mucous membrane' and 'pink and red tissue' removed because they appear to cause confusion.</i></p>

*After discussion she suggested “HPV **only** targets **specific types of cells only found in** the moist..... membrane.”*

“I kind of knew that; that’s kind of logical as where I got it [the cancer] is soft and pink.”

Another patient thought it could be a really useful message if explained (after hearing that the virus gets into particular type of cell that is found in the tissue of the areas listed in message 3). One thought the wording made sense: *“That’s as obvious as anything, because of where there is moist red and pink tissue, that is in the intimate areas.”*

membrane, such as inside the mouth or the genitals and anus.

11.
Smoking may worsen your prognosis, especially if you continue to smoke after diagnosis.

**Phase 1 rating:
7/30 participants included this message in their top 5**

Many patients thought this was important to know, but mainly as an anti-smoking message. Most thought it was ‘a given’ that smoking is not good for you. Many felt it was irrelevant as they don’t smoke.

“This is too general; smoking is relevant for everything. Also, smoking comes up as a topic anyway in the conversation with consultant; knowing this will not influence anything.”

“...very important for me, I was a smoker, this [cancer diagnosis] was what made me stop smoking; everybody thinks of smoking in relation to lung cancer and pulmonary issues; important to know this.”

12.
This is a sexually transmitted infection, but unlike other STIs, there is no need to inform previous partners about your HPV status. It’s up to you whether to tell your current partner.

**Phase 1 rating:
5/30 participants included this message in their top 5**

Only 5 patients ranked this message in the top 5, but many made comments. Some patients did not find the difference from other STIs obvious. Others found it an odd idea not to let others know what is going on. Also it is confusing because if they didn’t know they had it, they wouldn’t tell anyone about it anyway. One found it reassuring that you don’t have to worry about other people. Some felt it is the same as message 6, which says it better.

“It’s so long in starting, you don’t even know where these former partners are, so you can’t contact them anyway.”

“It’s up to individuals anyway, I don’t need to be told this. It’s up to you to disclose or not, however you feel.”

Most patients thought this was an important message. One commented that the message could be better phrased. He did not like the use of the word ‘worsen’ and also wasn’t sure that people would know the meaning of ‘prognosis’. One thought information should be added as to why this is the case, and information of where help is available. Another felt it was not necessary to have this message: *“Do I have to have this said to me all the time? Non-smokers don’t need to be told and smokers know they shouldn’t smoke.”*

If it is difficult to know whether you have HPV, a patient wondered whether this statement implied you should be aware of your HPV status, similar to HIV status and therefore be morally and legally obliged to disclose to current and future partners? But you wouldn’t know you had it until you got cancer? One felt that the message kind of implies it is not a serious enough thing to tell anybody about. Isn’t it possible that you’re giving somebody else cancer, in a roundabout way? You should tell future partners, give them a choice. A few people thought it rather odd to suggest that you might not want to be open and share this with your current partner.

“This is an individual decision, a personal choice, but I think it would be imperative to tell your current partner.”

However, others felt that the sexually transmitted label puts a stigma on it.

“...reading this statement makes me feel, oh gosh, I can’t believe what this is, that’s how it makes you feel...”

... add information about why this would be the case

... any change here would be to include where help to stop smoking would be available

This is a sexually transmitted infection, but unlike other STIs, there is no need to inform previous *or current* partners about your HPV status. ~~It’s up to you whether to tell your current partner.~~

...but unlike other *sexually transferred infections (STIs)*, there’s no need... It’s up to you whether to tell your current partner *whether you’ve had an HPV related cancer*

ADD: *because there is no treatment for HPV.*

It’s up to you whether to tell your current partner *and it is advisable to tell future partners.*

This is a sexually transmitted infection, but unlike other STIs, there is no need to inform previous partners about your HPV status.

If you are a smoker, giving up smoking may help your recovery.

Rephrased to make a more positive message and to shorten

Added to all 3 scripts (previously only in head and neck) on expert group advice.

There is no need to tell previous partners you have HPV. There is no test or treatment for it; most people clear the virus without treatment and without even knowing they had it.

First sentence shortened for clarity and readability. ‘Sexually transmitted infections’ removed to de-stigmatise. Statement about current partners removed because consensus seemed to be either that it would be right to tell your current partner, or that you would just naturally do so. Sentence added to explain why there is no need to inform previous partners

<p>13.</p> <p>There is no treatment for HPV infection but there's now a vaccination for people aged 9 – 26. It's a good idea for young people to be vaccinated before they become sexually active.</p> <p>Phase 1 rating: 15/30 participants included this message in their top 5</p>	<p>This was ranked highly and many made comments. Most agreed that this was a very important, reassuring and hopeful message for young people; it is relevant for prevention not post-diagnosis.</p> <p><i>"for my grandchildren, for future generations, it's got to be number 1."</i></p> <p><i>"Valid informative statement but not much good for people my age."</i></p>	<p>Patients agreed that this was a useful message, although one feared it will be a signal to young people that it is ok to be experimental and promiscuous. While one thought it implied vaccination for boys, another felt it important to add information to this message about vaccinating boys (privately and what it costs). One wondered whether he could have had it and another whether if she had the vaccination now, she might avoid contracting HPV again.</p>	<p>There is no treatment for HPV infection but there's now a vaccination for people aged 9 – 26. It's a good idea <i>a most effective</i> for young people to be vaccinated before they become sexually active.</p> <p>Add something about young people still needing to be cautious.</p> <p>It's a good idea for young people, <i>male and female, (or: boys and girls)</i> to be vaccinated before they become sexually active.</p>	<p>There is no treatment for HPV infection but there's now a vaccination to prevent it. It's best for young people to be vaccinated before they are sexually active.</p> <p><i>Message shortened for readability.</i></p> <p>There is no treatment for HPV infection but girls are now vaccinated against it in high school.</p> <p><i>Alternative message for gynae cancers</i> <i>This overlaps with other messages about intimate contact, now combined in message 1.</i></p>
<p>14.</p> <p>HPV can be passed without penetrative sex but it does require intimate physical contact.</p> <p>Phase 1 rating: 7/30 participants included this message in their top 5</p>	<p>Several patients thought messages 14 and 15 overlap and should go together and would have assumed full penetrative sex was necessary, so this is new information. It is important to know what is meant by intimate physical contact. It is also important to educate young people as they may think they are safe if they don't have full sex.</p> <p><i>"Some people would not think it could refer to the hands (so even though 14 and 15 are the same, 15 gives the better information)."</i></p> <p><i>"This is not something you need to be told after they've found cancer in clinic but it should be part of sex education in schools."</i></p> <p><i>"Does that mean by kissing, or is that oral sex? That's an important one then. So many young people are dying, education is definitely needed for them, to think twice about things."</i></p>	<p>None patients commented on this statement. One patient thought 'penetrative' could possibly a difficult word for some people, though she struggled to find a substitute. Others thought this message should be linked with message 7. Also that this is a better message than message 6 – less accusatory, less rough. Some patients felt that is repetition between 1, 6 and 14 – and that you don't want to overload people with information.</p>	<p>HPV can be passed without penetrative sex but it does require intimate physical contact, such as deep kissing etc (perhaps combine with other statements giving similar information)</p>	
<p>15.</p> <p>It can be passed by the hands from one intimate part of the body to another.</p> <p>Phase 1 rating: 6/30 participants included this message in their top 5</p>	<p>Many felt this message relates to message 14 above and could be combined with message 6 (and overlaps with message 21). Those without partners currently did not find it relevant. People were surprised that it can be passed on so easily. It showed how easy it is to catch HPV (although that might be interpreted as addressing feelings of guilt and blame as it implies there doesn't have to be full sex involved).</p> <p><i>"when you think these days how young people are actually doing stuff, this information needs to be out there as well."</i></p>	<p>Only four patients commented and some found this a worrying statement.</p> <p><i>"This is a kind of angst inspiring one; what does this mean, you have to wear rubber gloves or something. You have to think about it a little bit because it's basically about touching different parts of the body."</i></p> <p>Also whether the patient can pass it on to other parts of himself. One woman wondered if it could have travelled through her body (she had previously cancer of the cervix) to her throat? One worried about the possibility of being infected when caring for her mother (applying cream to the anus after radiotherapy)? One felt it overlapped with message 14.</p>	<p>HPV can be passed by the hands from one <i>by touching different</i> intimate parts of the body to another.</p> <p>Statement needs to make clearer how this process works; also not clear whether it is from one person to another or whether one person could infect other parts of their own body; statement as it stands is too vague</p>	<p><i>This overlaps with other messages about intimate contact, now combined in message 1.</i></p>

<p>16.</p> <p>About two thirds of oropharyngeal cancers (which can involve the tonsils, tongue base and soft palate) are caused by HPV.</p> <p>H&N cancer only</p>	<p>Oropharyngeal patients identified this as important to know, and be made aware of. One patient felt it was not information that was important to him. 3 rated it in their top 5 messages, whereas 1 said it was not important information.</p>	<p>Head and Neck cancer patients found this useful and some preferred it to the multi-site statement. Two questioned the use of ‘oropharyngeal’ and wondered whether it would be understandable. Change to Head and Neck. One patient preferred this message to message 3 because he thought that message might be more worrying to people because they would think about all the other cancers they could get, whereas another thought it redundant as covered in message 3. One patient thought it important because it gives patients a sense of where this disease might have come from. Another questioned then where does the other third come from? Another thought the message was too long: <i>“Because of the long list in brackets, by the time you get to the end of the sentence you have forgotten that at the beginning it says ‘about two thirds’.”</i></p> <p>Three patients commented and said they found this a useful factual statement. No changes suggested. One thought message 18 should come before this one.</p> <p><i>“This is a bold factual statement, simple straightforward (not necessarily shocking).”</i></p> <p>One thought it was necessary information as he thought that people might easily come to the conclusion that that HPV could be passed by (non-sexual) kissing.</p>	<p>About two thirds of head and neck cancers (involving the tonsils, tongue base or soft palate) are caused by HPV.</p> <p><i>“...<u>may be</u> caused by HPV.”</i></p> <p><i>“...<u>have been proven to be</u> caused by HPV.”</i></p>	<p><i>Combined in cancer-specific versions of message 3.</i></p>
<p>17.</p> <p>Oral HPV infection can be transmitted by oral sex as well as other forms of close sexual contact.</p> <p>H&N cancer only</p>	<p>Two oropharyngeal patients rated this in their top 5 messages, and that it was important to know.</p>	<p>One thought it was necessary information as he thought that people might easily come to the conclusion that that HPV could be passed by (non-sexual) kissing.</p>		<p>HPV can be transmitted by oral sex as well as other forms of intimate contact. (Head & neck cancer only)</p> <p><i>Shortened for readability</i></p>
<p>18.</p> <p>There is some evidence that HPV may be transmitted by “deep” or “French” kissing but there is no evidence of transmission by sharing drinks or kissing on the cheek</p> <p>H&N cancer only</p>	<p>Two oropharyngeal patients rated this in their top 5 messages and found it important and reassuring.</p> <p><i>“It’s important to put this one up. It could be something as innocuous as giving someone a snog.’ ‘This makes you feel better.”</i></p> <p><i>“Reassuring that I’m not going to pass anything on to my family.”</i></p>	<p>There were no suggestions for rewording. Four patients commented. One patient thought that if this is a statement based on hard scientific fact and can be made with confidence it is really important. Perhaps it should be made clearer that the risk is transmission from mucous membrane to mucous membrane so a peck on the cheek or a kiss on the forehead is not risky. Two others felt that the term ‘some evidence’ was not useful and one felt this message should be left out as there is no hard evidence, and the point has been made in earlier messages which make it clear that transmission is by intimate contact.</p> <p><i>“...better to keep to the ‘cut and dried’ messages and leave out the ‘maybe’ ones. They dilute the messages...”</i></p>	<p>There is some evidence that HPV may be transmitted by “deep” or “French” kissing but there is no evidence of transmission by, <i>for example</i>, sharing drinks or kissing on the cheek. <i>Hugging your friends and children does not involve a risk of transmission</i></p> <p>The phrase ‘there is some evidence’ is not helpful.</p> <p>‘deep’ or ‘french’ kissing sounds a bit cheesy.</p> <p>There is some evidence that HPV may be transmitted by passionate kissing but there is no evidence of transmission by sharing drinks or kissing on the cheek..</p>	<p>HPV may be transmitted by ‘deep’ or ‘French’ kissing but <u>not</u> by sharing drinks or kissing on the cheek. (Head and neck cancer only)</p> <p><i>‘There is some evidence that’ removed as it was thought imprecise and not useful, and message shortened for readability.</i></p>

19. You are likely to have a better outcome if your cancer has been caused by HPV because HPV-driven cancers respond better to treatment than other cancers.	This message was identified as important and reassuring by most of the Head & Neck patients. However one patient also advocated only telling people their cancer is caused by a virus, and leaving it at that. 7 rated it in their top 5 messages. <i>"Reassuring" (Because you might have a better chance of a more complete recovery)</i> <i>"This is very hopeful."</i>	Eight patients commented and some identified this as an important and potentially positive message. One questioned what "better outcome" meant? He felt consultants should have facts and figures to give to people.	Perhaps add 'You are likely to have a <i>significantly</i> better outcome' (<i>but only if that is really justified</i>)	Head and neck cancers caused by HPV usually respond better to treatment than other types. (Head and neck cancer only) <i>Shortened for readability.</i>
20. Nearly all anal cancers are caused by HPV. Anal cancer only	Although rated in the top 5 by 2 patients, few comments were made. One patient found this message to be redundant as it is also included in message 3.	Seven patients commented. Some felt that this statement raises the question of what the other percentage of anal cancers are caused by? One found it a harsh statement and would be softer if combined with 22. Another thought it was covered by message 3 and not needed. One thought this message should remain as a separate message because " <i>it drives the message home more forcefully.</i> "	Nearly all anal cancers are caused by HPV. <i>But it can also be caused by ???,</i>	<i>Combined in cancer-specific versions of message 3.</i>
21. Anal HPV can be transmitted by anal sex or by hand transmission or intimate skin-to-skin contact. Anal cancer only	The few patients who commented felt it was good know, but also that it overlapped with other messages. One felt it conflicted with message 10 and is similar to message 15 which is clearer. One found it irrelevant. 2 patients rated it in their top 5 messages. <i>"Is this gay? It's not relevant to me."</i>	Eight patients commented. Some patients struggled with the term 'anal sex'. However they did not come up with an alternative word. One tried to rearrange the words to de-emphasise anal sex. <i>"'Anal' is not a nice word! People assume anal sex... I don't want to be labelled. I don't want to have to justify myself."</i> Some felt this message was not needed as statement 15 already incorporated this. Another thought it linked to Message 20. <i>"This reinforces that you don't have to be gay, but hand transmission or intimate skin-to-skin contact is in a previous message, so repetition."</i>	Anal HPV can be transmitted by anal sex or by hand transmission or intimate skin-to-skin contact (<i>hand or penis</i>) not just by anal sex. Anal HPV <u>could</u> be transmitted by anal sex or by....	HPV can be spread to the anal area by intimate skin-to-skin contact or anal sex. (Anal cancer only) <i>Simplified for readability and 'softened' by not making 'anal' the first word.</i>
22. In women it is easy for HPV to be transferred between the genital and the anal area. Anal cancer only	This was new information for patients. Some commented that this information is only relevant for women. Another wished she had known how easily HPV could be transferred earlier, and another that it felt irrelevant as she already had cancer. 5 patients rated it in their top 5 messages. <i>"I didn't know that. It would have been nice if someone had said it's very easy to be transferred, so if you wipe yourself."</i>	Five patients commented. They thought this self-explanatory and useful. One patient suggested this was covered in message 15. No rephrasing was suggested.		In women it is easy for HPV to be transferred between the genital and the anal area. (Anal cancer only) <i>No changes</i>
23. You can't get cervical cancer without having HPV first. Cervical cancer only	Seven of the gynae patients chose it as one of their top 5 messages, and many others made comments. Most were not aware of this fact and felt it was important information for them, one saying she needed to know how she got cervical cancer, although another worried as she had read an article describing cervical cancer as a 'lifestyle cancer'. However, one said this message was not needed as this information was available on the internet. Another felt it important information but harsh " <i>...hits you in the face...</i> ". She suggested combining with message 5 or 8 to soften the impact of the message.	Only two patients commented on this message. One felt it was a very straightforward statement: " <i>... you can't take issue with that. It would have been good to know.</i> " The other said none of the doctors she had seen had mentioned this and was only told that her cancer was "through HPV." " <i>I asked 'What does that mean?' And he said 'from an infection' – well, he's got so many people to see...</i> ". No rephrasing suggested.		<i>Combined in cancer-specific versions of message 3.</i>

"I don't like this. It makes it sound like it blames you".

"I didn't know that. That was the start of it, that I didn't know."

24.
Nearly half of vulvar and two thirds of vaginal cancers are caused by HPV.

Gynae cancers only

Two patients thought this message was covered by other messages (3, 23), one of them adding that they did not find this additional information was helpful. Another felt the message was important as it gave context. 2 rated it in their top 5.

"...as it gives a context to the HPV", you want to know what has caused your cancer."

Four gynae patients commented on this message. One wondered why the numbers (percentages) are different between the vulvar and vaginal cancers if they are caused by the same virus? Another felt there was confusion and thinks that most people would consider vaginal cancer the same as cervical cancer, and this was supported by another patient as she felt it is easy for a lay person to group cervical, vulval and vaginal cancer together as one type of cancer. One commented on the words vulvar and vaginal and thought they should be clarified with (vulva) and (vagina) inserted.

Suggested message:

Vulvar cancer is not confined to older women. Anyone can get it. (*'I thought it was just thrush.'*)

This message was based on P's experience of being in hospital and seeing women 'aged 22- 77' with similar cancer. She thought it important for young women to be alerted to signs that something more serious may be wrong.

Tentative suggestion: Nearly half of vulvar (vulva) and two thirds of vaginal cancers (vagina) are caused by HPV.

Combined in cancer-specific versions of message 3.

25.

Supporting references for new message:

Powell NG, Evans M. Human papillomavirus-associated head and neck cancer: Oncogenic mechanisms, epidemiology and clinical behaviour. *Diagnostic Histopathology* 2015;21(2):49-64.

Chu A, Genden E, Posner M, Sikora A (2013) A Patient-Centered Approach to Counseling Patients With Head and Neck Cancer Undergoing Human Papillomavirus Testing: A Clinician's Guide. *Oncologist* 18(2): 180-189

You and your partner will have already shared whatever infections you have and no changes in physical intimacy are needed.

New message to address questions about infecting and re-infecting a partner (see comments about message 2)
You or your partner might be at a slightly higher risk of other HPV-related cancers, so you should report any symptoms to your doctor, but remember that these cancers are very rare.

26.

Supporting references for new message:

Edgren G, Sparen P. Risk of anogenital cancer after diagnosis of cervical intraepithelial neoplasia: a prospective population-based study. *Lancet Oncol* 2007; 8(4): 311–6.

Saleem AM, Paulus JK, Shapter AP, et al. Risk of anal cancer in a cohort with human papillomavirus-related gynecologic neoplasm (link is external). *Obstet Gynecol* 2011; 117(3): 643–9.

Gaudet M, Hamm J, Aquino-Parsons C. Incidence of ano-genital and head and neck malignancies in women with a previous diagnosis of cervical intraepithelial neoplasia. *Gynecol Oncol* 2014;134(3):523-6.

Fakhry C, D'Souza G (2013) Discussing the diagnosis of HPV-OSCC: Common questions and answers. *Oral Oncol* 49(9): 863-871

New message to address questions about another HPV-related cancer developing at another site (see comments about message 3)
